BioTrust Research Report

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Michigan Department of Community Health
MDCH
Rick Snyder, Governor
James K. Haveman, Director

Were you born in Michigan since July 1984? Were your children? This report is for everyone, but if you answered "yes" to these questions, it's even more important to read this report!

"Blood spots" are collected from every baby soon after birth for Newborn Screening. Newborn screening tests a baby for rare disorders that need to be found and treated right away. Often some of the blood spots are left-over after newborn screening is done. These spots are stored by the Department of Community Health in the Michigan BioTrust for Health. There are rules for how these stored blood spots can be used. This report provides details about research using stored blood spots. To learn more about the BioTrust, rules for blood spot use and your options, contact:

Michigan Department of Community Health- Michigan BioTrust for Health
www.michigan.gov/biotrust or 866-852-1247

Why are left-over newborn screening bloodspots useful for health research?

Researchers have already found over 160 factors in blood spots that may provide clues for health risks. Michigan's blood spots have aided this work. One study found DNA can be extracted from the spots and studied (unpublished research from Wayne State University). This allows use of blood spots in studies looking for genetic risk factors of disease. A study led by Minnesota researchers included Michigan blood spots to help discover genetic risks for childhood cancer (unpublished research). An on-going study is using Michigan's blood spots to see if they can be used for HLA typing. A person's "HLA type" may impact the ability to fight infections, respond to vaccines and find a donor for organ transplants.

Blood spots can help tell us which groups of people are at risk for certain diseases. One study found that hereditary hemochromatosis (body absorbs and stores too much iron) may be more common in non-Hispanic white people (published research). Medical problems from iron overload may be a health concern for this group.

Only basic, non-identifying information is kept with the blood spots when they are used for research. Blood spots' usefulness in health research will likely grow over time, but these studies have already shown how Michigan's blood spots can be used to further our knowledge.

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Spinal Muscular Atrophy (SMA)

SMA is a genetic disease that affects motor neurons (nerve cells in the spinal cord). Symptoms of SMA can affect babies, children or adults. In its most severe form, SMA is the most common lethal childhood disorder. Symptoms get worse with time and can lead to breathing and swallowing problems. Genetic testing can be done to find people with SMA prior to symptoms of the disease. Treatment for SMA is evolving but may depend on finding people before symptoms begin. Therefore, a study began in 2010 to discover whether blood spots could be used to test for the genetic changes in newborns that cause SMA. The first phase of the study revealed genetic testing for SMA could be successfully done on blood spots (published research). A second larger phase of the study has begun.

Newborn Screening Research

Severe Combined Immuno-deficiency Disorder (SCID) is a rare but possibly lethal disorder. Newborns with SCID are missing part of the immune system needed to fight infection. They must be found and treated very early in life. Newborn screening in Michigan allows babies with SCID to be found and treated at the earliest possible stage. This gives them the best chance to survive. Blood spots were used to develop Michigan's newborn screening for SCID. Studies continue to improve screening methods. SCID screening began in Michigan in 2012 and since then 3 infants have been found and have begun treatment.

Other studies have used Michigan's blood spots to improve newborn screening tests, develop new tests, and add disorders to the screening panel. This has led to ~5,000 newborns being found through newborn screening since 1965. Their disorders could be treated before serious permanent damage to their health.

On-Going Studies

Research can take years to complete. While waiting for results, we want you to know studies are currently underway using blood spots to look for causes of common conditions such as:

Autism • Attention Deficit Hyperactivity Disorder (ADHD) • Cerebral Palsy • Congenital Heart Defects • Persistent Pulmonary Hypertension • Sudden Unexplained Infant Death

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Effects of Toxins and Heavy Metals

It is well known that high levels of lead can affect the developing brain. Drinking alcohol during pregnancy can also lead to damaging effects on an unborn baby. On-going studies are using blood spots to see if the damage caused by lead and alcohol is related to gene expression– the process of turning genes on or off.

Unborn babies and children are exposed to second hand smoke when their mothers and other caregivers smoke. This can cause a higher risk for health problems such as low birth weight and asthma. The amount of exposure and effects vary by race. An on-going study using blood spots is looking at the racial differences in exposure to second hand smoke. This may lead to important public health interventions for people at highest risk.

Methyl mercury is a metal found in many freshwater fish. Eating too much fish during pregnancy can lead to high levels of mercury and damage to a baby's developing brain. A 2011 study by Minnesota Department of Health tested methyl mercury levels in blood spots from Michigan, Wisconsin and Minnesota babies living along the shore of Lake Superior. Normal levels were found in blood spots from Michigan babies but levels in the other states were slightly higher. Studies like this can alert health departments about the need for more education on how to eat fish safely during pregnancy.

We hope this report helps explain how Michigan's blood spots have been used in research. Much of the work using Michigan's blood spots is still on-going, thus results are not yet available. Personal results from research are not returned, but further details about these studies can be found at www.michigan.gov/biotrust. You may also contact the Department of Community Health with any further questions at 866-852-1247. This report will be updated quarterly. Thank you for taking the time to learn more about blood spots and their value in health research.